

DOCUMENT RESUME

ED 084 731

EC 060 506

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 TITLE Affective Reactions in Some Parents of Deaf-Blind Children.
 INSTITUTION Callier Hearing and Speech Center, Dallas, Tex.
 SPONS AGENCY Bureau of Education for the Handicapped (DHEW/OE), Washington, D.C.
 PUB DATE 16 Nov 72
 GRANT OEG-0-9-536003-4093
 NOTE 13p.; A Paper presented at the Southwest Regional Meeting of the American Orthopsychiatric Association (Galveston, Texas, November 16, 1972)
 EDRS PRICE MF-\$0.65 HC-\$3.29
 DESCRIPTORS *Adjustment Problems; Affective Behavior; Behavior Patterns; *Case Studies; *Deaf Blind; Emotional Problems; *Exceptional Child Services; Multiply Handicapped; *Parent Attitudes; Personal Adjustment; Psychological Needs

ABSTRACT

Emotional problems and behavioral patterns of parents who have deaf blind children are described clinically and in short case studies. Deaf blind young children are said to be isolated from their families due to lack of sensory cues; to display behaviors such as back arching and fear of walking; and to experience frequent health crises such as heart involvement. Stress in parents is described in relation to the mother's feelings (such as prenatal expectation of a perfect child) and the narcissistic insult she suffers when the child is defective. Discussed is the normal mourning period both parents experience which involves three sequential elements: numbness, disbelief, and withdrawal from the outside world; disappointment and feeling of loss with accompanying affective and physical symptoms; and intense re-experiencing of memories and expectations. It is maintained that mourning must be understood by both the helping professional and the mourner to allow defense mechanisms to organize and that only as the parents learn to cope with their feelings can they help the handicapped child. Five case studies are presented that show different affective reactions of parents. Given in one example is the case of 17-year-old Dave whose parents cannot surmount disappointment, pain, and anger and thus are unaware of Dave's needs to socialize even though Dave uses oral expressive language and braille and is on his way to college. Concern is expressed for disadvantaged families, and agencies are urged to assume responsibility for any child or family that seeks help.

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ED 084731

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AFFECTIVE REACTIONS IN SOME
PARENTS OF DEAF-BLIND CHILDREN

A Paper Presented
at the
Southwest Regional Meeting
of the
American Orthopsychiatric Association
in
Galveston, Texas
on
November 16, 1972

by

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Deaf-blind children are those "who have auditory and visual handicaps, the combination of which causes such severe communication and other developmental and educational problems that they cannot properly be accommodated in special education programs solely for the hearing handicapped child or for the visually handicapped child."*

Local programs are required to provide for parent participation.* Amplified in guidelines for programs, "the Regional Center is responsible for establishing professional consultative and counseling services for parents, teachers and other relevant persons so that they may understand better the social, emotional, communication, educational and other problems of deaf-blind children." (Program Administrative Manual, October 4, 1972.)

What are these children like? Their vision problem is severe to profound. They may have only light perception or enough vision to be legally blind. Eleonor Faye¹ points out that lack of or decreased vision leaves out the synthesizing factor without which a child cannot seem to make full use of hearing and touch. Sound does not mean much if a baby does not see what makes the sound.

Many deaf-blind children have no visual images of their own bodies, of family or of environment. They acquire knowledge primarily through taste, smell and touch.⁸ Vision impairment means

*Public Law 91-230, Title VI-Education of the Handicapped Subpart C-2--Centers and Services for Deaf-Blind Children 121.238. Determination of deaf-blind children and 121.240 Parent participation.

that the child does not see chewing and has to be taught to chew and to feed himself. Fear of walking must be overcome because he does not know where he is in space. The deaf-blind child gets no clues regarding spatial relationships from seeing or from sound.

Dr. Louis Cooper states, "Many of these children have spent two and one-half years lying on their backs waving their hands or poking their fingers in their eyes, arching their backs or rocking their heads and pounding the edge of the crib."¹

Hearing may be impaired from mildly to profoundly. Or, the child may be able to hear but unable to process sound. This, of course, isolates him. His ability to acquire language receptively or expressively is greatly limited. Communication is greatly limited.

Freedman and Brown in their study of the first eighteen months of life of a rubella baby state, "In addition to the absolute reduction and qualitative alteration of sensory input consequent upon the presence of defective end organs, the children are physically ill and difficult to handle and feed."⁶ In the first year or two, health crises which threaten their lives are not infrequent. Most of the rubella children we know have heart involvement to some degree from mild to critical. Some have liver and spleen enlargement. Some of the children have high palatal arches. Other anomalies may be present.

More often than not, the children we see are lagging in the acquisition of muscular control allowing for sitting, crawling,

walking. Without appropriate help, some of the children are on their backs for years.

Freedman points out that the (rubella) child's energy is devoted to the business of staying alive leaving little over for connecting socially even if the child had the vision to see the objects.⁶ Many of the mothers we know talk of their children's backs arching when picked up or when being held. These children fuss and cry when being held and quieten when left alone in the crib. Such responses to the mother's attentions may cut her off from trying to interact with her baby.

A number of professional people have been concerned with the stress experienced by parents and families who have handicapped children. Most of them describe certain components of parental reaction which appear to be common, in some degree, in all parental reactions to producing a handicapped child.

The process which the mother experiences while pregnant is discussed by Solnit and Stark¹⁹ and by Ross.¹⁸ They point out that the pregnant mother is involved with what the child will be like and her hopes for him. This is a time when the mother is clarifying her attitudes about her femininity, her identification with her mother and working on coming to grips with any unresolved conflicts with her mother.

The pregnant woman fantasizes a perfect child, imbuing it with attributes of self love and other loved objects (her mother, father, husband, siblings.) Another part of the feeling she has is fear she will produce a damaged child.

If the child is defective, it is the mother who experiences the greatest narcissistic insult. The mother experiences feelings of worthlessness, failure, helplessness and disappointment. If there is unresolved conflict toward her own mother, her sense of inadequacy is compounded. She has never measured up to her mother's expectations.

Although the mother may receive the greater narcissistic blow, both parents experience a period of mourning, grieving for the fantasied child. Mourning is a process which takes place over a period of time, eventuating in a healing over of the pain. This period of time is really not possible for parents of the impaired child because his needs and demands have to be met immediately.

The process of mourning contains three main elements which, while overlapping to some extent, occur in sequence. These are:

1. numbness, disbelief, withdrawal from involvement in the outside world.
2. disappointment, feeling of loss, with accompanying affective and physical symptoms.
3. intense re-experiencing of memories and expectations.

Mourning and its intrareactions are normal feelings experienced upon loss of a loved object. If the mourning reaction is not understood by the helping professional and the mourner, then it may turn into a persistent, depressed self-reproachful state.

Ross sees the mourning process as the first step in the person's attempt to cope with the crisis.¹⁸ It is his thought

that the withdrawal enables the mechanisms of defense to become organized. At the end of mourning the person's anxiety is handled by using coping devices or defense mechanisms to control the feeling.

Kozier found in her work with parents of blind children that the parents expended considerable energy in efforts to control anger and hostility.⁸ Latent feelings of self-doubt and inadequacy resurfaced. The parents experienced conscious and unconscious death wishes toward the blind child.

In our programs, we have seen parents in a variety of affective reactions to their particular child's handicaps. Many parents experience depression coming out of feelings of helplessness, impotence, defeat.

Manny* is the son of a young, black mother. He is a beautiful boy, now two and one-half years old, who at eleven months of age contracted encephalitis. His mother, a welfare client, never had much nor expected much. She reacted with depression but had the strength to go to a child-care agency begging that he be taken from her. When the agency could not help, she went home with her boy. There she became more depressed, began to think of suicide. Increasing her frustration was the added factor of fatigue because M. was wakeful, restless, making a screaming sound night and day.

Help came in the form of a Department of Public Welfare caseworker who immediately arranged for day care of Manny at a

*The real names and situations are disguised.

rehabilitation center. By the time we met them, this mother had become quite apathetic. She held M. and talked of his not hearing and not seeing with tears in her eyes.

We took M. into our program for deaf-blind children for half days, and he continued at the rehabilitation center for the balance of each day. In a year's time, the mother has not been to see him in the program or to talk to teachers or social worker. When M. was at home in the summer because both agencies were closed for vacation, the mother became more deeply depressed.

We are seeing this family regularly. The social worker visits and is helping the mother apply for institutionalization. The child has not been able to use help.

There are parents who live with a chronic sorrow, having experienced the mourning and arrived at a fairly realistic view of their child. Such are Sam's parents. They have maintained a life of their own. They have found ways to support each other. They delight in a second child. There is sadness about Sam and a desire to help him develop as his potential permits. They can express in words their frustration and pain as well as their joy when he progresses.

Sam is now 14 years of age. He was premature, arriving at six and one-half months through the mother's pregnancy. He lived in an incubator receiving oxygen to sustain his life. He suffered brain damage and retrolental fibroplasia. His hearing problem is one of processing.

At this point in time, the parents are confronted with Sam's need for institutionalization. Aware of their ways of coping, they are visiting institutions and discussed Sam's needs with our teaching staff. They are discussing their own needs, feelings and apprehensions with the program social worker.

Some parents seem unable to get through the process dealing with disappointment, pain and anger. Dave's parents seem to fit here. Unable to permit themselves to face their rage and disappointment, they deny the reality of his limitations. As a result, they are unaware of his needs to find his identity and socialize with young people. Instead, they put the pressure of excelling academically as first priority. Their use of denial as a coping device and the need to project responsibility and blame also prevent their use of help for themselves.

Dave is now 17. The younger of two sons, he is on his way to college. Dave had encephalitis at the age of nine months. He is legally blind, having only peripheral vision. His hearing problem is said to be a processing disorder. Dave uses oral expressive language. His preferred method of language input is braille.

He wants to know about physical differences in boys and girls. He wants to know how to "make conversation" with a girl. He fantasies a world of his own, driving a car, going from bar to bar to meet people. When asked about going to college or his feelings about having limiting sensory losses, his voice tone and posture change, he talks as if parroting his father.

Linnie's parents also are unable to move through the steps of mourning. They have not found themselves in relation to the tragedy of L's impairments. They are realistic at a rational level, but the basic feelings interfere with their acting at a rational level. They are still in the "medical stage" and realistically they continue to learn of additional health problems. They are aware of their sorrow and pain. They can talk some about frustration. They seem hung-up in their unrecognized rage. As a result, they relate to Linnie dutifully and indulge her in ways which undermine her development.

Both parents cope by avoidance of their pain and by not permitting themselves to feel. As a result, their own relationship and the family cohesion are extremely fragile. So is the mother's emotional well-being.

Linnie is a four year old girl with multiple handicaps as a consequence of the mother's having rubella two weeks after conception. Linnie is blind in one eye and has had a cataract removed from the other. She has glaucoma in both eyes, causing pain. We have been unable to define the extent of her hearing impairment. Other anomalies are enlarged spleen, liver, malformation of kidney tubes. This youngster cannot yet sit alone.

Cheryl's mother provides an example of a parent who functions fairly adequately except when confronted with recurring crises, which are common among these families. The mother becomes depressed again when confronted with an unmanageable crisis such as recent eye surgery for which the family could

receive no outside assistance.

Cheryl is 7 years old. She is a victim of congenital rubella and has been left with profound hearing loss, cataracts and glaucoma in both eyes. Cheryl was hospitalized four times in 1972, at enormous costs. Family income is good enough to preclude free medical services but not enough to survive continuing high expenses for the many medical services which Cheryl requires.

I have discussed a very small part of the concerns we have for these children and their families. We know there are families who are not making it. We know that the disadvantaged families are getting lost. Dr. Louis Cooper¹ makes the following plea: "First of all, each facility or agency should assume true responsibility for any child or any family that walks in its door."

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